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Determinants of Heart Failure Self-Care Maintenance and Management in Patients and Caregivers: A Dyadic Analysis

Julie T. Bidwell[1,*], **Ercole Vellone**[2,†], **Karen S. Lyons**[1,‡], **Fabio D'Agostino**[2,†], **Barbara Riegel**[3,§], **Raúl Juárez Vela**[4,†], **Shirin O. Hiatt**[1,‖], **Rosaria Alvaro**[2,‖], and **Christopher S. Lee**[1,‡]

[1]School of Nursing, Oregon Health & Science University, United States

[2]Department of Biomedicine and Prevention, University of Rome Tor Vergata, Italy

[3]School of Nursing, University of Pennsylvania, United States

[4]College of Nursing, University of San Jorge, Spain

Abstract

Disease self-management is a critical component of maintaining clinical stability for patients with chronic illness. This is particularly evident in the context of heart failure (HF), which is the leading cause of hospitalization for older adults. HF self- management, commonly known as HF self-care, is often performed with the support of informal caregivers. However, little is known about how HF dyads manage the patient's care together. The purpose of this study was to identify determinants of patient and caregiver contributions to HF self-care maintenance (i.e., daily adherence and symptom monitoring) and management (i.e., appropriate recognition & response to symptoms), utilizing an approach that controls for dyadic interdependence. This was a secondary analysis of cross-sectional data from 364 Italian HF patients and caregivers. Multilevel modeling was used to identify determinants of HF self-care within patient-caregiver dyads. Patients were 76.2 (*SD*=10.7) years, a slight majority (56.9%) was male, while caregivers were 57.4 (*SD*=14.6) years, and fewer than half (48.1%) were male. Most caregivers were adult children (48.4%) or spouses (32.7%) of patients. Both patients and caregivers reported low levels of HF maintenance and management behaviors. Several significant individual and dyadic determinants of self-care maintenance and self-care management were identified, including gender, quality of life, comorbid burden, impaired ADLs, cognition, hospitalizations, HF duration, relationship type, relationship quality, and social support. These comprehensive dyadic models assist in elucidating the complex nature of patient-caregiver relationships and their influence on HF self-care, leading to more effective ways to intervene and maximize outcomes.

Correspondence concerning this article should be addressed to: Julie T. Bidwell, Oregon Health & Science University School of Nursing, Mail code: SN-2N, 3455 SW US Veterans Hospital Road, Portland, OR, 97239-2941. Phone: +1 (503) 756-1996. Fax: (503) 494-4721. pfisterj@ohsu.edu.

*PhD Student

†Research Fellow

‡Associate Professor

§Professor

‖Research Associate

Appropriate disease self-management in the outpatient setting is an essential component of successful overall management of chronic illness in adults. In many contexts, community-dwelling individuals with chronic illnesses rely on informal caregivers – spouses, adult children, siblings, or other family members or friends – to help with daily adherence behaviors or to appropriately respond to symptoms of illness as they occur. In the United States, upwards of $450 billion worth of unpaid care is provided by informal caregivers each year (Feinberg, Reinhard, Houser, & Choula, 2011). Clinicians often interact with caregivers as though they were members of the healthcare team, relying on them to assist the patient with health behaviors, medication adherence, and symptom monitoring (Grady et al., 2000); heart failure (HF) is no exception.

A rapidly increasing number of adults are being diagnosed with HF (Heidenreich et al., 2013), a disorder that is marked by significant symptom burden, poor quality of life (QOL), and premature mortality (McMurray et al., 2012). In order to prevent exacerbation and progression of disease and reduce the risk of hospitalization and death, patients with HF must engage in a series of self-care behaviors to maintain clinical stability (self-care maintenance) and manage symptoms when they occur (self-care management) (Riegel et al., 2009). Not surprisingly, informal caregivers play a critical role in the effective management of HF in the outpatient setting (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Gallagher, Luttik, & Jaarsma, 2011; Salyer, Schubert, & Chiaranai, 2012). Yet, despite awareness that both patients and caregivers contribute to self-care and that patient and caregiver outcomes are often interdependent (Berg & Upchurch, 2007; Kim, Reed, Hayward, Kang, & Koenig, 2011; Klinedinst et al., 2009; Rayens & Svavarsdottir, 2003), there is a paucity of knowledge on the determinants of self-care maintenance and management behaviors within this dyadic (patient and caregiver) context. This gap in knowledge poses a major barrier to clinicians' ability to identify and intervene in cases of low levels of self-care, and hampers researchers' ability to appropriately conceptualize HF self-care and develop effective interventions that benefit both the patient and caregiver.

HF Self-Care

At an individual (patient) level, HF self-care has been conceptualized as a naturalistic decision-making process with two components: self-care maintenance and self-care management (Riegel & Dickson, 2008). Self-care maintenance refers to daily behaviors that a patient must do to maintain clinical stability, such as taking medications as prescribed, adhering to a low sodium diet, and monitoring for HF symptoms. Self-care management refers to behaviors in which a patient must engage when symptoms of HF occur, namely, recognizing the symptom as being related to HF, engaging in appropriate treatment (e.g. taking an extra diuretic, etc.), and evaluating whether the treatment adequately resolved the symptom (Dickson, Buck, & Riegel, 2011; Riegel & Dickson, 2008). Effective self-care has been recognized as a critical component of overall HF management (Jurgens, Hoke, Byrnes,

& Riegel, 2009) and has been associated with reduced clinical event risk for HF patients (Lee, Moser, Lennie, & Riegel, 2011).

Determinants of HF Self-Care

In patients, self-care is often impaired by multiple sequelae that characterize the complex syndrome of HF, such as depression (Holzapfel et al., 2009), sleep disturbances (Riegel, Moelter, et al., 2011), impaired cognition (Cameron et al., 2010; Harkness et al., 2013; Lee et al., 2012), high comorbid burden (Dickson et al., 2011), and decreased perception of declines in health (Gravely-Witte, Jurgens, Tamim, & Grace, 2010; Jurgens et al., 2009). Patient self-care management has also been shown to be associated with such factors as patient age (Holzapfel et al., 2009; Jurgens et al., 2009; Riegel, Lee, & Dickson, 2011; Seto et al., 2011), patient gender (Jurgens et al., 2009), HF duration (Jurgens et al., 2009; Oosterom-Calo et al., 2012; Riegel, Lee, et al., 2011), hospitalizations (Jurgens et al., 2009), general QOL (Lee, Suwanno, & Riegel, 2009), and HF-specific QOL or symptom burden (Altice & Madigan, 2012; Jurgens et al., 2009; Peters-Klimm et al., 2013; Riegel, Lee, et al., 2011; Seto et al., 2011).

Dyadic approaches to studying HF self-care hold great promise for elucidating key determinants of patient maintenance and management behaviors, and understanding caregiver contributions to those behaviors. Caregiver contributions to patient self-care can be conceptualized as the caregiver doing the behavior for the patient (e.g. the caregiver calling a healthcare provider for the patient when symptoms occur) or prompting the patient to do the behavior (e.g. the caregiver telling the patient to call a healthcare provider when symptoms occur) (Vellone, Riegel, Cocchieri, Barbaranelli, D'Agostino, Glaser, et al., 2013). Relatively little is known about caregiver or dyadic determinants of HF self-care, despite the important role caregivers play in HF patient outcomes. However good relationship quality and social support are considered key factors in better patient self-care (Dunbar et al., 2008; Graven & Grant, 2014; Riegel, Lee, et al., 2011; Riegel et al., 2009; Salyer et al., 2012; Stromberg, 2013). In addition, previous dyadic work on a subset of spousal dyads from the data used in this study provided evidence of significant actor and partner relationships between self-care and quality of life across dyads (Vellone et al., 2014). The current study expands upon this work by examining determinants of self-care in a larger sample of both spouse and non-spouse dyads using more comprehensive dyadic models.

Analyzing the HF Dyad

Most research on chronic disease management is undertaken at the level of the individual (i.e., patient or caregiver only). In order to better inform theory and develop a solid base of evidence for interacting with patients and caregivers in clinical practice, there is a clear and pressing need to acknowledge this interdependence and examine patients and caregivers within the context of the dyad. Such studies require appropriate methodologies that control for the interdependent nature of the data, as traditional analytic approaches are often unsuitable for handling responses from patients and caregivers within the same dyad (Lyons & Sayer, 2005). In particular, traditional approaches often require aggregating and

comparing data on patients and caregivers, thereby ignoring the relational aspect of the dyad and making it impossible to examine within and between dyadic effects.

Multilevel modeling has several advantages over traditional approaches to dyadic data, as within-dyad interdependence can be controlled, and between-dyad variability can be examined. Multilevel modeling also allows for the examination of actor effects (one's own characteristics predicting one's own outcomes) and partner effects (one's own characteristics predicting the outcomes of the partner) across dyads (Lyons, Sayer, Archbold, Hornbrook, & Stewart, 2007; Rayens & Svavarsdottir, 2003). Accordingly, the goal of this multilevel dyadic analysis was to 1) characterize HF maintenance and management behaviors within a dyadic context, and 2) identify individual- and dyad- level determinants of both patient and caregiver contributions to HF self-care maintenance and management behaviors.

Methods

Study Design

This was a secondary analysis of data from a multi-site, cross-sectional descriptive study of HF self-care behaviors conducted on a large cohort of patients and primary informal caregivers in Italy. The primary aims and detailed study procedures have been published previously (Cocchieri et al., 2014; Vellone et al., 2014). In short, HF patients from ambulatory cardiovascular clinics in 28 different Italian provinces were screened and offered enrollment by trained research nurses. Patients were eligible for enrollment if they: 1) were being seen at the clinic for a routine HF appointment, 2) had a diagnosis of HF confirmed by echocardiogram, 3) had clinical evidence of HF as outlined by European Society of Cardiology guidelines (McMurray et al., 2012), and 4) were willing and able to provide informed consent. Patients were excluded if they were less than or equal to 18 years of age, had an acute coronary event in the three months prior to enrollment, or had clear evidence of dementia. If the primary informal caregiver of an enrolled patient was present at the appointment, he or she was also offered enrollment in the study.

Ethical Approval

The parent study complied with the Declaration of Helsinki, ethics committees at each site approved the research protocol, and informed consent was obtained from all participants. This secondary analysis also was reviewed and approved by our institutional review board.

Data Sources

Demographics and clinical characteristics—Patients and caregivers completed self-report questionnaires that included basic demographic data (age, gender, marital status, education level, employment, income, and how patient and caregiver were related) and the study instruments described in the sections that follow. Clinical HF characteristics (ejection fraction, New York Heart Association (NYHA) Class, duration of HF, hospitalizations, medications) and comorbid conditions as assessed by the Charlson Comorbidity Index (Charlson, Pompei, Ales, & MacKenzie, 1987) were abstracted from the patient's medical record.

Caregiver and patient quality of life—Physical and mental QOL for both patients and caregivers were assessed using the physical and mental component summary scales of the Short Form-12 (SF-12) (Ware, Kosinski, & Keller, 1996); standardized scores range from 0–100 with higher scores indicating better QOL. The SF-12 is a health status measure that has been widely used in caregiving research and has been validated for use in Italy (Gandek et al., 1998). HF-specific physical and emotional QOL for patients was assessed using the Minnesota Living with Heart Failure Questionnaire (MLHFQ) (Rector, Kubo, & Cohn, 1987), a 21-item measure of the impact of symptoms of HF on patient QOL; physical and emotional summary scores were computed with higher values indicating worse QOL.

Patient impairment in activities of daily living—The Barthel Index (Mahoney & Barthel, 1965) was used to evaluate patient impairment in 10 activities of daily living (ADLs). Response categories for each item vary; but, scores were standardized to range from 0–100, with higher scores indicating less impairment.

Patient cognition—Patient cognition was assessed using the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), an 11-item clinical assessment tool. Item scores vary depending on the question or task, and item scores are summed to produce a score ranging from 0 to 30, with higher scores indicating better cognition. The commonly-used cutoff of 24 was used to indicate cognitive dysfunction (Mitchell, 2009).

Caregiver strain—Caregiver strain was assessed using the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989), a 24-item instrument that measures strain on multiple dimensions. The total score for the CBI was used in this analysis. The item-response scale is a five-point Likert scale ranging from 0 to 4, and scores are summed, with higher scores indicating greater strain. The CBI was selected for this study because it is the only measure of caregiver strain that has been shown to be valid and reliable in an Italian population (Marvardi et al., 2005).

Caregiver perceived social support—Caregiver perceived social support was assessed using a subscale of the Carers of Older People in Europe Index (COPE Index) (Balducci et al., 2008). The COPE Index is a 15-item instrument that measures the positive and negative impacts of caregiving as well as the quality of social support received. It was developed and validated in multiple European languages and countries (Balducci et al., 2008; McKee et al., 2003) and was used to study caregiving of elderly people in Italy (Vellone et al., 2011). The 4-item perceived caregiving social support subscale was used in this analysis. The item-response scale for the COPE Index is a 4-point Likert scale ranging from 1 to 4; scores are summed with higher scores indicating greater perceived support (possible range 4–16).

Perceived quality of the relationship between patient and caregiver—Perceived quality of the relationship between patient and caregiver was assessed using a single item. Patients responded to an item designed by the research team, "How do you judge your relationship with your caregiver?" (Likert scale ranging from 1 to 5, with higher scores indicating greater perceived relationship quality). Caregivers responded to an item from the COPE Index, "Do you have a good relationship with the person you care for?" (Likert scale ranging from 1 to 4, with higher scores indicating greater perceived relationship quality).

Patient and caregiver contributions to HF self-care maintenance and management—Patient-reported contributions to HF self-care maintenance and management were assessed using the Italian version of the Self-Care of HF Index version 6.2 (SCHFI) (Vellone, Riegel, Cocchieri, Barbaranelli, D'Agostino, Antonetti, et al., 2013), a 22-item instrument that measures self-care maintenance (daily behaviors such as medication and dietary adherence, physical activity, symptom monitoring, etc.) and self-care management behaviors (recognizing and responding appropriately to symptoms of HF when they occur). Item response scales vary, and scores are standardized to range from 0 to 100, with higher scores indicating better self-care; the cutoff for "adequate" self-care is 70 or above (Jurgens et al., 2009). Caregiver-reported contributions to patient HF self-care maintenance and management behaviors were assessed using the Italian version of the Caregiver Contribution to Self-Care of HF Index (CC-SCHFI) (Vellone, Riegel, Cocchieri, Barbaranelli, D'Agostino, Antonetti, et al., 2013), a parallel version of the SCHFI designed for administration to caregivers. The items on the CC-SCHFI mirror the items on the SCHFI; however, instead of asking how often the respondent engages in their own self-care, the items ask how often the caregiver recommends that the patient engage in the given behavior, or how often the caregiver does the behavior for the patient if they are unable.

Statistical Analysis

The sample was described using means and standard deviations for continuous variables and n and frequency for binary or categorical variables. Two dyadic cross-sectional multivariate outcomes models were constructed using HLM 7 (Raudenbush, Bryk, & Congdon, 2011). The advantages of using this analytic approach with dyadic data include: 1) the patient-caregiver dyad (rather than the individual patient or caregiver) is the unit of analysis, 2) within-dyad interdependence is controlled, and 3) both actor effects (e.g. patient characteristics predicting patient outcomes) and partner effects (e.g. patient characteristics predicting caregiver outcomes) can be examined across dyads (Sayer & Klute, 2005).

The cross-sectional dyadic multivariate outcomes model used in this analysis is a two-level hierarchical linear model that allowed for simultaneous estimation of regression coefficients for both patients and caregivers while controlling for interdependence within dyads. Two models (one for self-care maintenance & one for self-care management) were examined. In the Level 1 model, scores for self-care maintenance or management were estimated for patients and caregivers as a function of observed responses and measurement error. The Level 1 (within-dyad) equation for the self-care maintenance model is as follows:

$$\text{SCMaintenance}_{ij} = \beta_{1j}(\text{PATIENT}_{ij}) + \beta_{2j}(\text{CAREGIVER}_{ij}) + r_{ij}$$

In this equation, $\text{SCMaintenance}_{ij}$ represents the self-care maintenance score i ($i = 1, \ldots k$ responses per dyad) for dyad j. PATIENT and CAREGIVER are indicator variables that take on the value of 0 or 1 depending on whether the response is from the patient or the caregiver (e.g. if the response was obtained from a patient, the PATIENT variable would take on a value of 1 and the CAREGIVER variable would take on a value of 0), making β_{1j} the latent self-care maintenance score for the patient, and β_{2j} the latent self-care maintenance score for the caregiver. The error term in the equation is represented by r_{ij}. A similar model is run for self-care management.

Before proceeding to Level 2, a chi-square test was used to confirm that the variability around the average scores for self-care maintenance or management were significantly different from zero. If this was the case, then the variability around those averages was predicted in Level 2 models by adding independent variables. Thus, at Level 2 (between-dyad), β_{1j} and β_{2j} become the dependent variables in two separate simultaneous regression models: one simultaneous regression for self-care maintenance and one simultaneous regression for self-care management. A combined theoretico-empirical approach was used for the selection of independent determinants for the models. In addition to the theoretical factors of age, gender, general QOL, comorbid illness burden, cognition, duration of HF, hospitalizations, HF-specific QOL, relationship quality, and social support (as reviewed in the introduction), we included additional factors identified in a priori testing within the sample (correlated with self-care maintenance or management at p 0.1). This resulted in the inclusion of ADL impairment, relationship type, and caregiver strain in the models. Selected independent variables were divided into three categories (patient non-HF characteristics, patient HF characteristics, and relationship/caregiving variables) and added to predictive models in blocks to facilitate the evaluation of model fit (deviance, χ^2) by variable category.

Results

The characteristics of the sample (*n*=364 dyads) are presented in Table 1. On average, patients were approximately 20 years older than caregivers, and although there was a slightly higher proportion of male as opposed to female patients, the gender proportions for caregivers were nearly equivalent. The majority of patients and caregivers were married, but not necessarily to one another, as the majority of caregivers were adult children. Caregivers were more educated than patients, and most caregivers were employed. In general, both members of the dyad rated the quality of their relationship with the other member as good. Most patients had NYHA Class II or III HF, and the duration of HF was highly variable, ranging from 1 month to 20 years.

Determinants of Self-Care Maintenance

Level 1 results revealed that patient HF self-care maintenance and caregiver contributions to patient HF self-care maintenance were generally low on average (patient: 51.77 ± 0.76, $p < 0.001$; caregiver: 54.48 ± 0.92, $p < 0.001$), and were significantly variable across dyads (patient: $\chi^2 = 487.97$, $p < 0.001$; caregiver: $\chi^2 = 700.77$, $p < 0.001$). Determinants of patient self-care maintenance and caregiver contributions to self-care (Level 2 results) are presented in Table 2. Patient HF-specific emotional QOL was the only significant factor to influence the self-care maintenance of both patients and the contributions of caregivers. Other significant factors only influenced the self-care maintenance of either the patient (patient physical QOL, comorbidities, ADL impairment, cognition, number of hospitalizations, and patient-reported relationship quality, as well as caregiver gender and perceived social support), or the contributions of the caregiver (duration of HF). Each block of variables (patient non-HF characteristics, patient HF characteristics, and caregiver/relationship characteristics) resulted in a significant improvement in model fit at $p < 0.001$ or lower.

Determinants of Self-Care Management

Level 1 results revealed that patient HF self-care management and caregiver contributions to patient HF self-care management were also low (patient: 48.20 ± 0.97, $p < 0.001$; caregiver: 53.61 ± 0.97, $p < 0.001$) and highly variable across dyads (patient: $\chi^2 = 626.80$, $p < 0.001$; caregiver: $\chi^2 = 633.11$, $p < 0.001$). The significant determinants of self-care management and caregiver contributions to self-care management (Level 2 results) were distinct for patients and their caregivers (Table 2). For patients, male gender and higher caregiver physical QOL were associated with worse self-care management, and better cognition and patient-reported relationship quality were associated with better self-care management. For caregivers, greater patient comorbid illness burden was associated with fewer contributions to patient self-care management, while nonspousal relationship, higher frequency of patient hospitalization, better caregiver-reported relationship quality, and better caregiver perceived social support were all significantly associated with more contributions to patient self-care management. When independent variables were added in blocks, blocks of patient non-HF characteristics and relationship/caregiving variables resulted in a significant improvement in model fit over the previous blocks at $p < 0.01$ or lower, while the block containing patient HF characteristics did not ($p = 0.12$).

Discussion

In this secondary analysis of data from 364 Italian patient-caregiver dyads in HF, significant determinants for patient HF self-care and caregiver contributions to patient self-care were identified. Importantly, both individual and dyadic effects were identified in models predicting patient and caregiver contributions to maintenance and management. Furthermore, several of these identified determinants were partner effects (e.g., patient's physical QOL on caregiver contributions to patient self-care management). Together, these findings underline the need to examine HF self-care maintenance and management in the context of the patient-caregiver dyad in order to better understand these critical behaviors and the transactional nature of disease management within HF dyads. Several of our findings are particularly noteworthy. Namely, the role of patient and caregiver gender, cognition, HF-specific QOL, relationship type and relationship quality, and the role of caregiver strain and perceived social support will frame this discussion.

Gender and Self-Care

Given that there was no gender difference in HF self-care management in previous and large cross-national samples (Lee et al., 2011), our finding that patient gender (male) was a significant determinant of (worse) patient self-care management was somewhat surprising. There is evidence, however, of a gender difference in symptom recognition (Jurgens et al., 2009), which is the first and essential component of self-care management. Thus, it is possible that the worse self-care management observed among men in this sample is a function, at least in part, of worse symptom recognition. The specific sociocultural context in which this study was conducted (Italian patients and caregivers) may also explain discordance of our findings with prior published work, or it may be that gender becomes significant for patients when we consider the dyadic context of self-care by controlling for the influence of the caregivers.

Very little is known about the influence of caregiver gender on HF self-care. In this sample, it was caregiver gender (female) that was a significant determinant of patient (better) self-care maintenance. In the broader caregiving literature there is evidence that female caregivers report greater investment of time in caregiving (Pinquart & Sorensen, 2006) and tend to provide more social and emotional support to the care recipient than male caregivers (Neal, Ingersoll-Dayton, & Starrels, 1997). It is possible that this additional emotional support from female caregivers motivates patients to engage in better self-care, or that it is protective against some of the aspects of the heart failure syndrome that are associated with lower levels of self-care (e.g. depression). It is also possible that there may be differences in quality or type of care provided depending on whether the caregiver is the daughter of the patient versus a female partner. Although this analysis examined relationship type (spousal or nonspousal) as a determinant of self-care (discussed in a following section), the interplay between gender and relationship type is complex, and likely also includes interactions with age. Thus, there is an opportunity to examine this important relationship – about which very little is currently known – in future research.

Cognition and Self-Care

In alignment with previous findings that even mild cognitive impairment can have a substantial impact on self-care (Lee et al., 2012), we observed a relationship between cognitive dysfunction and low levels of patient self-care maintenance and management. It should be noted that, on average, the degree of cognitive dysfunction in the sample was fairly low and thus potentially undetectable by caregivers. In fact, perhaps reflecting caregivers' inability to recognize mild cognitive dysfunction in their care recipients, patient cognition was not a significant predictor of caregiver contributions to patient self-care. On the other hand, the lack of a significant relationship between patient cognitive dysfunction and caregiver contributions to patient HF self-care may be reflective of caregivers' desire to support or promote the autonomy and independence of the older adult, particularly in situations of adult-child caregivers where the dyad does not cohabitate.

HF-Specific QOL and Self-Care

There is mounting evidence that symptoms of HF are related to self-care. In this analysis, QOL related to physical symptoms of HF was not a determinant of patient self-care or caregiver contributions to patient self-care. This may be a function of a generally poor ability to recognize physical symptoms in this sample overall (Cocchieri et al., 2014). In contrast, QOL related to emotional symptoms of HF was a significant determinant of better self-care maintenance for patients and higher contributions to patient self-care maintenance from caregivers. It is possible that the emotional symptoms of HF are particularly evident and distressing for patients and caregivers, and thus serve as a motivator or reminder of the severity of disease and the need to attend to routine behaviors in an effort to prevent hospitalization. One might expect to see a similar relationship between greater HF specific emotional QOL and better self-care management that we did not observe in this sample; but, emotional symptoms may not be readily linked to HF by patients and caregivers, and thus may not trigger engagement in HF-specific self-care management behaviors. It is important to educate patients and families that engagement in effective self-care maintenance is necessary even in situations where physical symptoms are well-controlled but emotional

symptoms are pervasive. It should be noted that this observed effect is not an argument to leave emotional symptoms of HF unaddressed, but rather suggests that emotional distress related to HF may be particularly burdensome for both patients and caregivers. It should be noted that a previous analysis of a subgroup of spousal dyads from this dataset (n=138) focusing on general physical and mental QOL as an outcome (Vellone et al., 2014) had somewhat contrasting findings. It is possible that relationships with QOL in patient-caregiver dyads change when the QOL construct examined is specific to symptoms of HF, rather than exclusively general QOL. It is also possible that the additional examination of nonspousal dyads and the adjustment for multiple confounders in the model contributes to different findings.

Relationship Type and Quality and Self-Care

To our knowledge, this is the first study to examine the association between *type* of relationship and HF self-care, and we observed that non-spousal relationship type was a significant determinant of higher caregiver contributions to patient self-care management. Nonspousal caregivers are more likely to live away from the patient and have competing demands (e.g., young children, jobs), and thus the actions that they take to help patients manage their symptoms may require travel and/or communication by phone. That is, symptom management does not occur in the course of normal interactions within a household, and it may be easier to recognize problem-based interactions as being contributions to the patient's HF self-care management. It is also possible that caregivers who do not live with the patient may feel pressure to be particularly diligent in helping patients manage symptoms, as they are not able to be physically present to respond to declines in patient health.

It also appears that better relationship quality is associated with better patient self-care and caregiver contributions to patient self-care, although it is the individual's own perception of the quality of the relationship that was important. Social support is considered a major determinant of expertise in self-care behaviors (Dickson et al., 2011), and the relationship that the patient has with their primary caregiver is arguably the most influential supportive relationship in the patient's life. If the patient perceives that the quality of that relationship is good, they may feel more supported in attending to their own health. This is a particularly promising finding, as the quality of the relationship between two known, accessible individuals in a caregiving dyad (e.g. a husband and wife) may be more feasibly targeted for intervention than a patient's overall social network. Furthermore, in the context of self-care management, better caregiver-reported relationship quality predicted higher contributions to patient self-care from the caregiver. Thus, interventions tailored to relationship quality may have an added advantage of improving self-care in the dyad overall, in addition to its known protective benefits for caregivers (Park & Schumacher, 2014).

Caregiver Strain and Perceived Social Support and Self-Care

Caregiver strain was not a significant determinant of either patient self-care or caregiver contributions to patient self-care. One possible explanation is that the caregivers in this sample reported very low levels of strain on average, and that the measure used in this study (the only validated measure of caregiver strain available in Italian) was designed for

dementia caregiving and had not been previously utilized in the study of HF. Alternatively, in multivariate models that adjust for relationship quality, strain may not retain significance in the model due to relationship quality being a known protective factor against strain (Lyons, Stewart, Archbold, & Carter, 2009).

Social support is thought to be important in HF; but ours is the first report of perceived caregiver social support as a determinant of both patient and caregiver contributions to self-care. It is reasonable that patients may perceive their caregiver's social supports as an extension of their own existing support, and/or patients (particularly family members) may share many of the same supportive relationships as their caregivers. The influence of perceived social support on caregiver management may reflect caregivers' particular need to rely on family and/or friends when responding to patient symptoms, which can arise quickly and without warning. Additionally, caregivers with less external support may have less capacity to urgently step away from everyday commitments to assist a patient with an exacerbation of symptoms.

Strengths and Limitations

This study has several notable strengths. In particular, the sample of dyads utilized in this analysis is much larger than typical dyadic studies in HF, which allows for the implementation of more complex multivariate models that included patient, caregiver and dyad characteristics. Additionally, the statistical approach used allows for the prediction of self-care maintenance and management behaviors for both patient and caregiver while controlling for dyadic interdependence; this is not possible using most traditional approaches which assume independence of observations. The analysis of such a large sample using methods that are robust and appropriate for patient-caregiver dyads provides information that enhances understanding of these behaviors in a real-world, dyadic context.

This study also has some important limitations. First, this is an analysis of cross-sectional data, which precludes conclusions about directionality or cause of the identified relationships. Second, the sample is limited to a single European country, and thus there may be sociocultural influences unique to this population that may limit applicability in other countries. Third, this study enrolled caregivers who accompanied patients to appointments, and did not pursue caregivers who were not present at the time the patient was enrolled. It is difficult to surmise whether there might be differences in these two groups, although this may also be considered a strength, given that providers will likely only have opportunities to interact with caregivers if they are present with the patient at a clinical encounter. Finally, the wording of the CC-SCHFI does not allow for distinction between caregivers providing verbal recommendation to patients to do self-care behaviors and caregivers who are actively doing self-care for the patient. However these two aspects are consistent with the definition of caregiver contributions underpinning the CC-SCHFI. It should also be noted that the Situation-Specific Theory of Heart Failure Self-Care was recently updated (Riegel, Dickson, & Faulkner, 2015). In addition to other revisions, this updated theory explicitly includes influences of "multiple players" (e.g. family or friends) on patient self-care. Our understanding of self-care in patient-caregiver dyads can be further expanded in future research using instruments based on this revised model.

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Conclusions

In this analysis of 364 patient-caregiver dyads in HF, we identified multiple determinants of patient HF self-care maintenance and management behaviors and caregiver contributions to those behaviors. Although the traditional emphasis in studies of HF self-care is on individual patient models that include limited caregiver and relationship variables, this analysis showed that a combination of patient, caregiver, and dyadic characteristics predicted both patient self-care and caregiver contributions to patient self-care. Because the majority of HF patients have informal caregivers to assist them with disease management, utilizing robust analytic approaches to dyadic data in this context holds great promise for elucidating the complex nature of these relationships and their influence on HF self-care.

Acknowledgments

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Table 1

Characteristics of the Sample (n=364 dyads)

	Patient mean (SD) or n (%)		Caregiver mean (SD) or n (%)	
Age	76.26	(10.72)	57.44	(14.63)
Female	157	(43.13%)	189	(51.92%)
Married	198	(54.40%)	253	(69.51%)
High School Ed	96	(26.37%)	193	(53.02%)
Employed	45	(12.36%)	177	(48.63%)
Caregiver Relationship to Patient				
Spouse			119	(32.69%)
Adult Child			176	(48.35%)
Other			69	(18.96%)
RQ[a]	4.19	(1.12)	3.13	(0.90)
CBI			29.71	(23.56)
COPE			10.60	(2.51)
Comorbidities	3.09	(1.31)		
MMSE	23.79	(6.61)		
SF-12 PCS	34.93	(9.97)	45.29	(8.96)
SF-12 MCS	42.25	(9.82)	47.38	(9.74)
NYHA Class				
I/II	205	(56.32%)		
III/IV	156	(42.86%)		
EF (%)	44.31	(10.94)		
HF Duration (mos)	59.65	(48.61)		
Hospitalizations	0.75	(0.84)		
MLHFQ Physical	22.04	(8.38)		
MLHFQ Emot	11.42	(5.57)		
Self-Care Maint	53.40	(15.68)	54.78	(18.58)
Self-Care Mgmt	49.07	(19.55)	53.98	(18.23)

Note: High School Ed: attained High School education or beyond; RQ: Relationship Quality; CBI: Caregiver Burden Inventory; COPE: Caregiver perceived social support subscale of the COPE Inventory; Comorbidities: Charlson Comorbidity Index; MMSE: Mini-Mental State Examination; SF-12 PCS: Physical Component Summary of the SF-12; SF-12 MCS: Mental Component Summary of the SF-12; NYHA Class: New York Heart Association Functional Class; EF: Ejection Fraction; HF Duration (mos): Duration of heart failure in months; Hospitalizations: Hospitalizations within the past year; MLHFQ Physical and MLHFQ Emot: Minnesota Living with Heart Failure Questionnaire Physical and Emotional Subscales; Self-Care Maint: Self-Care Maintenance; Self-Care Mgmt: Self-Care Management

[a]Relationship Quality instrument uses a different scale for patients vs. caregivers: Patient possible range is 1–5, Caregiver possible range is 1–4

Table 2

Multilevel Models (Level 2) Predicting HF Maintenance and Management (n=364 dyads)

	Maintenance Model				Management Model			
	Patient		Caregiver		Patient		Caregiver	
Independent Variables	β	(SE)	β	(SE)	β	(SE)	β	(SE)
Patient Non-HF Characteristics								
Patient Age	0.01	(0.07)	−0.12	(0.12)	0.01	(0.10)	0.08	(0.10)
Patient Gender (Male)	−2.55	(1.46)	0.47	(1.96)	−4.71*	(1.99)	−0.34	(2.03)
Patient Physical QOL	−0.27*	(0.10)	−0.13	(0.12)	0.15	(0.14)	0.43*	(0.13)
Patient Mental QOL	−0.03	(0.09)	0.02	(0.12)	−0.05	(0.12)	−0.15	(0.12)
Patient Comorbidities	1.26*	(0.64)	0.56	(0.64)	−0.70	(0.81)	−2.31*	(0.77)
Patient ADL Impairment	0.13*	(0.05)	0.01	(0.06)	0.02	(0.06)	−0.04	(0.07)
Patient Cognition	0.30*	(0.14)	0.35	(0.19)	0.38*	(0.19)	−0.06	(0.19)
Patient HF Characteristics								
HF Duration (Months)	0.03	(0.02)	0.05*	(0.02)	0.03	(0.02)	0.03	(0.02)
Hospitalizations	−2.03*	(0.89)	0.69	(1.11)	1.16	(1.28)	3.12*	(1.40)
HF-Specific Phys QOL	−0.10	(0.14)	−0.08	(0.17)	0.12	(0.18)	0.21	(0.18)
HF-Specific Emot QOL	0.42*	(0.21)	1.04*	(0.23)	0.08	(0.25)	0.14	(0.22)
Caregiver/Relationship Characteristics								
CG Gender (Female)	3.45*	(1.40)	2.76	(1.73)	0.40	(1.90)	−2.78	(1.91)
Non-spousal Relationship	−1.52	(1.56)	0.47	(1.87)	3.07	(2.07)	6.72*	(1.96)
Caregiver Physical QOL	−0.12	(0.09)	−0.20	(0.11)	−0.42*	(0.12)	−0.16	(0.13)
Caregiver Mental QOL	0.08	(0.08)	0.16	(0.10)	0.03	(0.11)	0.09	(0.10)
Patient-reported RQ	1.87*	(0.75)	1.79	(0.95)	2.28*	(0.92)	0.34	(0.77)
Caregiver-reported RQ	0.40	(0.84)	0.32	(1.13)	2.00	(1.19)	2.23*	(1.06)
Caregiver Strain	−0.06	(0.04)	−0.06	(0.05)	−0.04	(0.05)	−0.05	(0.05)
Caregiver Social Support	0.65*	(0.31)	0.53	(0.37)	0.51	(0.40)	1.17*	(0.42)

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Independent Variables	Maintenance Model				Management Model			
	Patient		Caregiver		Patient		Caregiver	
	β	(SE)	β	(SE)	β	(SE)	β	(SE)
Explained Variance (Cohen's f^2)	75.91% (3.15)		33.76% (0.51)		26.56% (0.36)		29.04% (0.41)	

Note: QOL: Quality of Life; HF-Specific Phys QOL: HF-Specific Physical Quality of Life; HF-Specific Emot QOL: HF-Specific Emotional Quality of Life; CG Gender: Caregiver Gender; RQ: Relationship Quality

*
$p < .05$